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Understanding the dynamics of relationships and the resource perceived by parents of children with Rare Diseases: Implications for support and Well-Being

Abstract:

Introduction: Rare genetic syndromes, (≤ 5 cases per 10,000 individuals), present significant psychological and emotional challenges for affected adolescents and their families. Adolescence is a critical period for identity formation and social development, during which youth with rare diseases may face unique difficulties, including social isolation and complex medical needs. This study aims to explore the dynamics of parent-child relationships in families affected by rare diseases, examining how perceived resources influence both family and individual well-being.

Methods: The study included two groups: a clinical group comprising 29 adolescents with rare diseases and their 56 parents, and a control group of 29 healthy adolescents. Data were collected using the Parent/Child Relationship Questionnaire (PCRQ) and the Strengths and Difficulties Questionnaire (SDQ) to assess relationship dynamics and psychological well-being. Statistical analyses, including Chi-square tests, independent t-tests, and two sample Wilcoxon tests, were conducted to compare the groups and variables.

Results: Significant differences were found between the clinical and control groups, with the clinical group showing higher SDQ scores ($p < 0.05$). Notably, discrepancies were observed in parent-child perceptions; parents tended to overestimate the warmth and support perceived by their children.

Conclusions: These perceptual differences underscore the need for targeted interventions to enhance communication and understanding between parents and children. Psychological support strategies and parental training programs could promote a more empathetic family environment, ultimately improving the well-being of adolescents with rare genetic syndromes and their families.

Biography

Margherita Siciliano earned a specialist degree in the Psychology of Cognitive Processes and Functional Recovery from the University of Campania “Luigi Vanvitelli” in 2010. She completed her specialization in Cognitive Psychotherapy in 2016 and obtained her PhD in Medical, Clinical, and Experimental Sciences from the same University in 2019. From 2019 to 2022, Dr. Siciliano volunteered at the Child Neuropsychiatry Department. Since 2022, she has been working as a Research Fellow at the University of Campania Luigi Vanvitelli, focusing on providing psychological care for pediatric patients with severe obesity. She has been invited as a speaker for national and international conferences focused on developmental psychology or developmental disorders. Her research interest is focused on developmental age, developmental psychology, and neurodevelopmental disorders.